

## Short Communication

# Association between caregiver burden in family and hemodialysis compliance of chronic kidney disease patients in Aceh, Indonesia

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## Abstract

Patient compliance toward undergoing treatment determines its success rate. Unfortunately, the compliance among hemodialysis patients is concerning. Supports from family has been suggested influence the patient compliance, especially from a family member who acts as a caregiver. The aim of this study was to determine the association between the level of caregiver burden and compliance in hemodialysis patients. A cross-sectional study was conducted at Dialysis Installation at Dr. Zainoel Abidin Hospital, Banda Aceh, Indonesia. The study sample was family members who accompanied hemodialysis patients. The minimal number of patients was determined of which 67 respondents were required and therefore recruited. Caregiver burden was collected using direct interview using Caregiver Burden Assessment questionnaire. The results revealed that twenty-four respondents (35.8%) had moderate caregiver burden, while there were only nine respondents (13.4%) had very low caregiver burden. The majority of the hemodialysis patients were non-compliant (n=38, 56.7%). A Chi-squared test indicated a significant association between the status of caregiver burden and the patient compliance to hemodialysis ( $p=0.011$ ). These findings stress the importance of addressing caregiver burden in ensuring the compliance of patients receiving hemodialysis.

**Keywords:** Chronic kidney disease, hemodialysis, caregiver, caregiver burden, compliance

## Introduction

Chronic kidney disease (CKD) is a pathophysiological process with various etiologies, resulting in a progressive decline in kidney function, often irreversible, where permanent renal replacement therapies (dialysis or kidney transplant) are required [1]. Despite its importance, patient compliance to hemodialysis therapy is reported low [2]. One of the most contributing factors in determining patient compliance, is the support from the accompanying family members during the hemodialysis [3]. Unfortunately, accompanying the patient to hemodialysis therapy could also negatively impact the social life of the family members. Oftentimes, caregivers might experience increased levels of stress and anxiety. As emphasized previously, long term therapy contributes to a caregiver burden [4].

Taking care of hemodialysis patients can be difficult and overwhelming for caregivers. Despite being at risk of developing health problems themselves and being considered "hidden



patients," caregivers are often overlooked. A study showed that caregivers of hemodialysis patients face significant burden, which can have a negative impact on their overall well-being [5]. Increasing caregiver burden and decreasing quality of life can lead to complications such as depression. There is also a significant relationship between increased caregiver burden and reduced care provided by caregivers, because caregiver burden can have a very devastating impact on individuals [6]. In the case of CKD, a previously study revealed that the prevalence of caregivers with high level and moderate level burdens could reach 23.5% and 49%, respectively [7]. Similarly, another study reported that the prevalence of high level and moderate level burdens of caregivers of patients with CKD were 29% and 34.2%, respectively [8]. In Indonesia, studies on the burdens of family caregivers of CKD patients receiving hemodialysis are still underreported, especially in Aceh. Therefore, the aim of this study was to investigate the caregiver burden and its association with patient compliance to hemodialysis.

## Methods

### Study design and participants

An observational analytic study with a cross-sectional design was conducted at the hemodialysis installation in Dr. Zainoel Abidin Hospital, Banda Aceh, Indonesia from November to December 2019. Respondents were family (spouse, relatives, child, siblings, or grandchild) who accompanied hemodialysis patients for at least 3-month long as suggested by previous studies [5,9], and were willing to participate in the study. Signed informed consents from all respondents were collected prior to the study. Respondents who met the criteria were interviewed using the Caregiver Burden Assessment instrument to assess the level of caregiver burden. Hemodialysis patient compliance was assessed and classified.

### Study variables and data collection

Some variables were assessed and collected in this study: (1) demographic data (gender, age, marital status, education, employment status, and relationship with patient); (2) duration of patient care; (3) the level of patient compliance to hemodialysis; and (4) the assessment of caregiver burden. Patient compliance assessment followed the criteria published previously [10], where a patient was considered non-compliant if they missed one or more hemodialysis sessions or shortened a session by more than 10 minutes per month. Caregiver burden was assessed by the Caregiver Burden Assessment instrument. The questionnaire has been validated for Indonesian population in a previous study [11]. The questionnaire was adapted from Zarit Burden Scale and The Montgomery Borgatta Caregiver Burden Scale, which consists of 39 items that measures subjective and objective burden with Cronbach's alpha values of 0.936 and 0.925 for subjective and objective burdens, respectively [11-13].

### Statistical analysis

All analyses were conducted using SPSS v.21 (IBM, Armonk, New York, United States). Frequency (n) and percentage (%) were used to describe the samples. The association between the level of caregiver burden and hemodialysis compliance was analyzed with Chi-squared test. A *p*-value of <0.05 was considered to be statistically significant in the analyses.

## Results

### Characteristics of respondents

Seventy-two caregivers were initially identified; 5 of them were excluded and 67 of them were included as respondents in this study. The five caregivers were excluded because they did not meet 3-month minimum duration of caring the patients. Characteristics of the respondents in this study are presented in **Table 1**. Most of the respondents were female (n=55, 82.1%) and aged 36–45 years (n=19, 28.4%). Number of married caregivers (n=48, 71.6%) was higher than those unmarried (n=19, 28.4%). Respondents holding a high school degree certificate were predominant (n=32, 47.8%). Thirty-one respondents (46.3%) were employed, while 36 others (53.75%) were unemployed. In terms of the caregiver relationship with the patient, most of them

were spouses (n=35, 52.2%) and children (n=23, 34.3%). As many as 28 (41.8%) and 26 (38.8%) respondents had taken care the patient for <1 and 1–3 years, respectively, while the rest (n=13, 19.4%) more than 3 years. Chi-squared analysis suggests no statistically significant differences in all characteristics variables between caregivers of compliant and non-compliant hemodialysis patients ( $p>0.05$ ).

**Table 1. Caregivers characteristics and their association with CKD patient compliance to hemodialysis**

Characteristics	Total n (%)	Compliant n (%)	Non-compliant n (%)	p-value
Sex				0.246
Male	12 (17.9)	7 (58.3)	5 (41.7)	
Female	55 (82.1)	22 (40.0)	33 (60.0)	
Age (years)				0.150
17–25	17 (25.4)	7 (41.2)	10 (58.8)	
26–35	6 (9.0)	5 (83.3)	1 (16.7)	
36–45	19 (28.4)	10 (52.6)	9 (47.4)	
46–55	13 (19.4)	4 (30.8)	9 (69.2)	
56–65	9 (13.4)	3 (33.3)	6 (66.7)	
>65	3 (4.5)	0 (0.0)	3 (100.0)	
Marital status				0.331
Married	48 (71.6)	19 (39.6)	29 (60.4)	
Unmarried	19 (28.4)	10 (52.6)	9 (47.4)	
Education				0.290
Elementary school	4 (6.0)	0 (0.0)	4 (100.0)	
Junior high school	8 (11.9)	3 (37.5)	5 (62.5)	
Senior high school	32 (47.8)	16 (50.0)	16 (50.0)	
College	23 (34.3)	10 (43.5)	13 (56.5)	
Employment status				0.838
Employed	31 (46.3)	13 (41.9)	18 (58.1)	
Unemployed	36 (53.7)	16 (44.4)	20 (55.6)	
Relations with patient				0.805
Spouse	35 (52.2)	15 (42.9)	20 (57.1)	
Relative	1 (1.5)	1 (100.0)	0 (0.0)	
Child	23 (34.3)	9 (39.1)	14 (60.9)	
Sibling	6 (9.0)	3 (50.0)	3 (50.0)	
Grandchild	2 (3.0)	1 (50.0)	1 (50.0)	
Duration of care (years)				0.598
<1	28 (41.8)	13 (46.4)	15 (53.6)	
1–3	26 (38.8)	12 (46.2)	14 (53.8)	
>3	13 (19.4)	4 (30.8)	9 (69.2)	

### Association between caregiver burden level and hemodialysis compliance

Burdens of caregivers of the hemodialysis patients are presented in **Table 2**. Out of 67 respondents, 24 (35.8%) of them had moderate level of burden. High level burden was observed among 12 respondents (17.9%). The number of non-compliant patients were higher (n=38, 56.6%) as compared to those who were compliant (n=29, 43.4%). The lowest proportion of compliant patients was observed in those with highly burdened caregivers (n=2, 6.9% of compliant patients). Seventeen patients (44.7% of non-compliant patients) were non-compliant when their caregivers had moderate level burden. The Chi-squared analysis suggested a significant association between caregiver burden and hemodialysis compliance among CKD patients ( $p=0.011$ ) (**Table 2**).

**Table 2. Relationship between caregiver burden level and hemodialysis compliance of CKD patients**

Caregiver burden level	Total n (%)	Compliant n (%)	Non-compliant n (%)	p-value
Very low	9 (13.4)	6 (20.7)	3 (7.9)	0.011*
Low	22 (32.8)	14 (48.3)	8 (21.1)	
Moderate	24 (35.8)	7 (24.1)	17 (44.7)	
High	12 (17.9)	2 (6.9)	10 (26.3)	

\*Statistically significant at  $p<0.05$

## Discussion

Out of 67 respondents in this present study, most of them were females, aged 36–45 years, and married. These demographic characteristics are similar with that of previous studies investigating caregiver burdens [7,8,14]. A study conducted in Iran, recruited respondents where 68.6% of them were women [7]. High proportion in female could be attributed to the fact that women, under the social norms, are more dominant in parenting role. Being older than 35 years old is suggested to be associated with higher caregiver burdens [14]. Age implicates the physical abilities and mental health of the individuals when carrying the task as a caregiver [14]. In a previous study, a significantly larger proportion of the respondents were married ( $n=44$ , 86.3%) [7]. According to the findings from a previous study in Indonesia, married individuals might face different challenges resulting in significantly higher caregiver burden when compared to those unmarried [8]. In this present study, the majority of the respondents were senior high school graduates and unemployed. Similarly, previous studies also suggested that being high school graduates and unemployed are common among caregivers of hemodialysis patients [2,7,15]. Higher education level has been suggested to contribute to better social support and coping mechanisms in dealing with problems, hence lower burden [16]. Other factors affecting the caregiver burden are family relationship and duration of the treatment [6,9]. In this present study, we found that most of the caregivers were spouses of the patients, in which this caregiver–patients relationship is common [9]. Additionally, herein, most of the respondents had only acted as caregivers for less than a year. It was suggested that the subjective burden of caregivers became less as they coped with the condition [17]. However, it is worth noting that the objective burden is unlikely to be affected by the treatment duration owing to the fact that the financial, time, and energy requirements for caring the patients remain constant [17].

Herein, there was a high number of respondents found to have experienced a moderate level of caregiver burden. Caregivers with moderate-level burden are common among hemodialysis cases [6,17]. As discussed earlier, age, gender, employment and income status, duration of care, educational status, and health conditions could influence the caregiver burden. A study specifically noted that higher burden in caregivers is derived from higher number of responsibilities [17]. In this present study, a significant association was observed between the levels of caregiver burden and patient compliance to hemodialysis. Hemodialysis patients might lose their compliance as they receive less family support following the increasing caregiver burden. As suggested previously, family support determines patient compliance to the treatment [4,6]. Support from family caregivers is crucial to increase the motivation of the patient in undergoing hemodialysis program [18]. Those receiving adequate family support were more likely to comply with the treatment program [3]. Therefore, it is of importance to address the burden of the family members and identify problems they face when acting as caregivers.

There are some limitations in the study that need to be considered. This is a cross-sectional study with a relatively small sample size and only performed at a single healthcare center, so the results may not be generalized to a larger populations. The analysis was performed on overall caregiver burdens, without further classifying it into objective and subjective burdens. Moreover, the correlation between the caregiver burden and patient compliance was not analyzed in this study.

## Conclusion

Caregiver burden is significantly associated with patient compliance to hemodialysis. Though the data is insufficient, it is likely that higher caregiver burden reduce the family support and patient motivation, which eventually lead to lower compliance. As family members hold a key role in the treatment, it is crucial to address their problems while acting as caregivers. Further research with more respondents and deeper analysis is still required to determine factors affecting patient compliance to hemodialysis program.

## Ethics approval

This study was approved by the Health Research Ethics Committee of Dr. Zainoel Abidin Hospital Banda Aceh prior to conducting the study (No. 316/EA/FK-RSUDZA/2019).

### Competing interests

The authors declare that there is no conflict of interest.

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### Underlying data

Derived data supporting the findings of this study are available from the corresponding author on request.

### How to cite

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